

# **Sustaining and Expanding ART Access in a Post–Global Fund Context: Lessons from Estonia**

**July 2008**

**Access to Essential Medicines Initiative**



**OPEN SOCIETY INSTITUTE**  
Public Health Program

# Table of Contents

About this publication .....	2
Acronyms and abbreviations .....	3
<b>1. Introduction.....</b>	<b>4</b>
1.1 Global Fund's worldwide impact and sustainability issues .....	4
1.2 Estonia as a post-Global Fund example .....	5
<b>2. Country-specific background information .....</b>	<b>7</b>
2.1 Overview of Estonia's HIV epidemic .....	7
2.2 Basics about HIV treatment policies and uptake .....	8
<b>3. The Global Fund program in Estonia .....</b>	<b>10</b>
<b>4. Challenges related to post-Global Fund transition .....</b>	<b>12</b>
4.1 Funding and budget support .....	13
4.2 Government's level and extent of preparation .....	14
4.3. Lack of consistency and coordination among government agencies regarding HIV/AIDS service responsibilities .....	16
4.4 Restrictive contracts .....	18
4.5 Civil society's effectiveness and relations with the government .....	18
4.6 Care and services for prisoners .....	20
4.7 Lack of generic ARVs .....	21
4.8 Problem and priority areas in regards to services scale-up .....	22
<b>5. Lessons learned and recommendations .....</b>	<b>25</b>
<b>Appendix 1. Civil society's 2007 public appeal on HIV/AIDS funding allocations ..</b>	<b>29</b>
 <b>Appendix 2. Key HIV prevention challenge: Lagging uptake and access to substitution treatment.....</b>	 <b>31</b>

## About this publication

The sustainability of programs supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria will be one of the most important issues in global health over the next several years. Once programs end, who or what will be responsible for taking over—and expanding, as needed—the projects and initiatives launched through the Global Fund? Will crucial services such as HIV treatment continue to be delivered to those in need? Will momentum be lost because of capacity, skills, and financial constraints at national and local levels?

Such questions are already being addressed in a handful of countries. One of those nations is Estonia, where the country's sole Global Fund program, which helped ramp up HIV/AIDS services, ended in October 2007. This publication examines developments prior to and following the program's end, including steps taken by the government and civil society in regards to HIV/AIDS funding and responsibilities in the future. It focuses particularly on availability and uptake of antiretroviral treatment (ART), the cornerstone of efforts to achieve universal treatment access for people living with HIV around the world.

All national and local contexts differ of course. However, the observations from and lessons learned in Estonia may prove instructive to stakeholders across the spectrum in other countries where such transitions must eventually take place. One overall message should be clear: it is never too early to start thinking about these things, especially for civil society advocates. Ensuring commitment to the sustainability and, ultimately, expansion of vital care and support initiatives has not been a simple task even in a relatively wealthy and stable country such as Estonia.

Preparation and methodology. The primary author of this report was Jeff Hoover; it was commissioned and supported by the Open Society Institute (OSI). Research centered on a review of relevant documents and interviews in Estonia in late April 2008. Those interviewed included government officials, representatives from civil society organizations involved in the HIV/AIDS response, and people living with HIV. Citations throughout the report point to sources of information and observations.

## **Acronyms and abbreviations**

AIDS =	Acquired Immune Deficiency Syndrome
ART =	antiretroviral treatment
ARV =	antiretroviral
CCM =	Country Coordinating Mechanism
EHPV =	Estonian Network of People Living with HIV
Global Fund =	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV =	human immunodeficiency virus
IDU =	injecting drug user
MoSA =	Ministry of Social Affairs
NGO =	nongovernmental organization
NIHD =	National Institute for Health Development
PLHA =	people living with HIV and AIDS
TB =	tuberculosis
UNAIDS =	Joint United Nations Programme on HIV/AIDS
VCT =	voluntary counseling and testing
WHO =	World Health Organization

### **Note on text:**

Unless specified otherwise, all figures marked by “\$” are U.S. dollar amounts.

## **1. Introduction**

### **1.1 Global Fund's worldwide impact and sustainability issues**

In less than seven years of existence, the Global Fund to Fight AIDS, Tuberculosis and Malaria has become one of the world's largest sources of health-related assistance, both in terms of scope and distributed resources. As of May 2008, as it was awaiting proposals for its eighth round of funding, the Global Fund had approved more than 500 grants around the world totaling some \$10.74 billion. At least 120 countries had benefited directly from at least one grant (including multi-country regional grants), with several having successfully applied multiple times.<sup>1</sup>

The Global Fund describes itself as a financing mechanism, not a program administrator. It therefore relies on projects and programs to be developed, implemented, monitored, and evaluated by national stakeholders. Such institutional flexibility is the main reason that individual grants vary in size from more than \$150 million to less than \$5 million depending on a country's population, the disease(s) for which funds are requested, proposals' intended outcomes, and how and through which entities resources are distributed and services implemented.

Some policies and regulations are universal and relatively detailed, however. The Global Fund's guidelines contain specific reporting requirements, for example, and the maximum duration of every single grant is five years. Thus, although the vast majority of the hundreds of Global Fund programs around the world have yet to conclude, they will all eventually end. In some countries and contexts, Global Fund assistance will continue through different programs initiated in other funding rounds. Even in such cases, however, the differences in each program in terms of scope, focus and approved funding mean that adjustments will need to be made in service delivery at the national and local levels.

The key point is that Global Fund programs are not indefinite, regardless of local needs. Moreover, even existing programs could face resource constraints should donors to the Global Fund itself reduce their support or fail to honor pledges. That possibility is not so far-fetched in a world where economic downturns can strike with little warning and governments of wealthy nations regularly face domestic pressure to limit foreign aid.

Whether anticipated or sudden, the end or sharp reduction in Global Fund support could have dire consequences—especially in developing countries with relatively high burdens of HIV, TB, and malaria, three of the world's most debilitating and deadly diseases. Global Fund assistance has improved the health and well-being of millions of people who otherwise might be dead or severely ill. The ripple effects of reduced sickness and morbidity on families, communities, and entire societies are equally profound.

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<sup>1</sup> Regularly updated information about the Global Fund, including all individual grants, is available online at its own website ([www.theglobalfund.org](http://www.theglobalfund.org)) and that of Aidspace ([www.aidspace.org](http://www.aidspace.org)), an independent watchdog and supporting organization.

Although the Global Fund is not the only provider of essential resources in these nations, it has been a vital one in many. Its involvement has been particularly extensive in developing and expanding HIV/AIDS service delivery, which is not entirely surprising given that two thirds of the grant funds allocated to date have been through its HIV/AIDS component. Among other things, the more than \$6 billion allocated through that component have supported

- the scale-up in more than 100 countries of antiretroviral treatment (ART) access;
- the roll-out of HIV prevention and education campaigns and associated materials (such as condoms); and
- anti-stigma initiatives designed and led by community groups and people living with HIV.

Sustaining the programs initiated through the Global Fund is therefore of crucial interest to those benefiting, directly or indirectly, from its assistance. Such programs can be costly, though, especially for poorer nations that in many cases have the greatest needs. They can also be difficult to administer and monitor effectively because of human capacity constraints. Some of the gaps can likely be addressed by other aid sources, including bilateral and multilateral agencies. However, in many cases responsibility for sustaining Global Fund programs—and expanding them, if and when needs arise—will rest primarily with national stakeholders: government agencies and domestic healthcare providers, local civil society, and the private sector.

Adequately preparing for and managing post–Global Fund transitions will be stern tests of societies’ commitment to build on important health-related achievements. As they move forward, those involved will need to make fundamental and difficult decisions in terms of how scarce resources are allocated and utilized throughout society. They should consider it an ongoing priority to understand and learn lessons from developments in other countries that have faced or are facing similar challenges. The contexts will never be the same, but the ultimate goals should be. Ideally, they are to

1. **sustain** levels of service achieved by Global Fund programs by their official end, and
2. **expand** the reach of those services as part of an effort to achieve universal access, especially for life-prolonging treatment and care.

Those two goals sound reasonable from just about any perspective—yet it is not as easy to achieve such goals as to recognize that they are priorities. That is why careful and ongoing consideration of developments elsewhere can be helpful.

## 1.2 Estonia as a post–Global Fund example

The list of potentially useful Global Fund transition examples is limited to date: as of May 2008, few countries had reached the point where all Global Fund programs had ended.

Estonia is one country that can properly be considered to have “graduated” beyond the Global Fund. At first glance, Estonia is not a nation that would appear to have much in

common with other Global Fund recipients. It has just 1.3 million people; is relatively wealthy and politically stable; is a member of the European Union; and is home to perhaps 10,000 people living with HIV at most. The conditions are worse and the needs greater in just about every other recipient nation.

Yet Estonian government authorities, supported by civil society, nonetheless felt the need more than five years ago to apply for Global Fund assistance and to rely on it to build what policymakers hope will be a viable, effective, and sustainable AIDS response. That objective is shared by every nation engaging with the Global Fund, regardless of the specific contexts.

Equally important and instructive is the fact that the end of the Global Fund program in Estonia was not seamless and uncomplicated, despite the country's comparatively favorable social, economic, and political factors. Government and civil society stakeholders had, and continue to have, different perceptions of the quality of service delivery over the years. They also are not equally confident in regards to the sustainability of HIV prevention and treatment programs initiated through the Global Fund.

Such differences will undoubtedly arise in every country and context where the Global Fund operates, and they are likely to be particularly noteworthy in regards to access to HIV treatment services. Determined advocates around the world continue to press governments and funding entities to make universal access to ART not just a pledge, but a reality. Some 3 million people were on ART by April 2008, but even that number represents less than half of those thought to be in need.

Some observers assert that universal access is neither achievable nor sustainable from any perspective; most of them argue that resources should be focused primarily on prevention. That view is refuted not only by most advocates, but by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund itself. They contend that prevention and treatment are inextricably linked within a comprehensive and ultimately effective AIDS response paradigm based on the following belief: increased access to ART is a humane and compassionate approach that can also have important impacts on HIV prevention efforts. As such, it should be a major priority of all funders, including the Global Fund, and all governments and service providers engaged in AIDS responses.

Most stakeholders in Estonia accept the importance of ART access and uptake and have made it a post-Global Fund priority; so too will their counterparts in other countries in the future. Therefore, this early observation of key HIV treatment issues in Estonia is likely to prove instructive and insightful. This report considers some of the main issues raised by stakeholders in Estonia and offers recommendations designed to improve and smooth processes elsewhere.

## 2. Country-specific background information

### 2.1 Overview of Estonia's HIV epidemic

Estonia regained its independence less than two decades ago when the Soviet Union collapsed. Not only does it have the smallest population of the former Soviet republics (1.3 million people), but it is also the richest—a distinction it held throughout most of the Soviet era. The country has barely paused during the early years of transition. Economic growth over the past decade has been among the highest in Europe, although the first signs of a sudden and largely unexpected slowdown were noted in early 2008.

Wealth is of course relative, and Estonia has far to go before catching up to most other countries in the European Union, which it joined in 2004. Pockets of poverty remain, especially among the ethnic-Russian community. Native Russian speakers comprise a significant minority, more than 25 percent of the population, and are concentrated in Tallinn, the capital, and the northeastern part of the country.

Ethnic Russians have also been disproportionately affected by HIV. The epidemic caught the country off guard when it first became apparent in the late 1990s among injecting drug users (IDUs) in and around the city of Narva, in the northeast. The cumulative number of registered HIV cases totaled less than 100 before 1999, but 390 new cases were registered in the following year alone.<sup>2</sup> That number more than tripled in 2001, when 1,474 new cases were registered. The sudden surge prompted the then-minister of social affairs to declare a “concentrated epidemic” and begin to consider more comprehensive strategies to respond to the crisis.<sup>3</sup>

As it turned out, 2001 was the peak year in terms of new registered cases. The number declined over the next few years before leveling off at about 700 new cases per year. The Estonian Health Protection Inspectorate reported 633 newly registered cases in 2007,<sup>4</sup> which brought the cumulative official total to 6,364 cases. However, UNAIDS estimates that the real number of cases in Estonia may be higher than 10,000.<sup>5</sup> Still, most nations with HIV epidemics would gladly trade their case burdens with either estimate. Yet it is a significant and worrisome statistic in such a small country. With adult HIV prevalence above 1 percent, Estonia has one of the highest HIV rates in Europe (surpassed only by Ukraine and, perhaps, Russia). Its rate of new diagnoses continues to lead Europe.<sup>6</sup> The

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<sup>2</sup> From Estonia progress report to UNAIDS, 2008.

[http://data.unaids.org/pub/Report/2008/Estonia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Estonia_2008_country_progress_report_en.pdf).

<sup>3</sup> Lizette Alvarez, “HIV surge catches tradition-bound Estonia off guard,” *New York Times*, February 15, 2004.

<sup>4</sup> From Estonia progress report to UNAIDS, 2008.

[http://data.unaids.org/pub/Report/2008/Estonia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Estonia_2008_country_progress_report_en.pdf).

<sup>5</sup> From Estonia progress report to UNAIDS, 2008.

[http://data.unaids.org/pub/Report/2008/Estonia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Estonia_2008_country_progress_report_en.pdf).

<sup>6</sup> As cited by the World Health Organization, “Evaluation of Fighting HIV/AIDS in Estonia,” April 2008. [www.euro.who.int/Document/E91264.pdf](http://www.euro.who.int/Document/E91264.pdf).



problem will be around a long time as well, given that individuals between 15 and 24 years of age comprise 80 percent of the newly diagnosed.

The epidemic has devastated the drug using community. Far more than half of those diagnosed to date contracted HIV through contaminated injection material; one survey from 2005 estimated that more than 60 percent of 13,800 IDUs in Estonia were HIV-positive.<sup>7</sup> However, IDUs' share of officially registered cases is declining, falling over time from 90 percent of those diagnosed in 2001 to less than 50 percent each year after 2004.<sup>8</sup>

## **2.2 Basics about HIV treatment policies and uptake**

The National Institute for Health Development (NIHD) oversees the Estonian government's AIDS response, including the direct implementation of policy decisions and programs. A division of the Ministry of Social Affairs (MoSA), NIHD was established in 2003—not coincidentally the year the Global Fund program started (see Box A).

NIHD's HIV treatment structure calls for individuals who test positive for HIV to be referred to infectious-disease specialists. Those specialists, who currently consult with patients in five cities, supervise all aspects of healthcare provided to PLHA, including the provision and monitoring of ART.

About 95 percent of all Estonians have health insurance, which is paid for through a state fund (the Estonian Health Insurance Fund) financed by a 13 percent levy on salaries. All employed individuals and pregnant women are automatically insured under that system and receive most healthcare services free of charge above and beyond quarterly fees of 50 Estonian kroons (\$5). Additional fees, usually no more than 50 kroons, are levied for certain "special" services, including<sup>9</sup>:

- home visits by primary practitioners;
- consultations with providers of specialized medical care;
- hospital stays;
- dental care (for adults); and
- medicines purchased in pharmacies.

The 5 percent or so of the population who are not covered through this fund often fall through the cracks, however. Generally speaking, the only subsidized or free services for them are emergency medical services. Special provisions cover uninsured individuals with certain conditions, including HIV and TB. Provisions for PLHA are built into the government's national HIV/AIDS program (see Box A). Most notably, HIV-positive

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<sup>7</sup> From Estonia progress report to UNAIDS, 2008.

[http://data.unaids.org/pub/Report/2008/Estonia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Estonia_2008_country_progress_report_en.pdf).

<sup>8</sup> National Institute of Health Development, "Estonian Program of Global Fund to Fight AIDS, Tuberculosis and Malaria," December 2007.

<sup>9</sup> The Estonian Health Insurance Fund's compensation levels differ depending on factors such as age and income. Patients' fees for these "special" services may therefore differ as well.

individuals can receive health care (including ART) free of charge in the public sector—with all fees waived—even if they are not employed. One major exception is that treatment for hepatitis C, a condition common among IDUs, is not available free of charge to those not enrolled in the insurance fund.

#### **Box A**

##### **THE NATIONAL HIV/AIDS STRATEGY AND GOVERNMENT ENTITIES' ROLES AND RESPONSIBILITIES**

The Estonian government's HIV/AIDS response is spearheaded by the National Institute for Health Development (NIHD), a division of the Ministry of Social Affairs (MoSA) that was established in 2003. Although the institute's overall objective, as per its website, is "the ongoing development of health and continuing improvement of the quality of life of the Estonian population," NIHD also has specific and important responsibilities regarding HIV/AIDS. In particular, it is charged with implementing and overseeing key health-related strategies and programs, including the government's National HIV/AIDS Prevention Strategy 2006–2015. In that role, it is "responsible for the monitoring and evaluation of all prevention activities and [developing] minimum standards for different services." It is supposed to coordinate these activities with "executive partners" including "the Ministries of Internal Affairs, Education, Justice and Defense."

The current national strategy replaced one introduced by MoSA in 2002. The new one was developed in 2005 as part of an effort to better coordinate and integrate other governmental agencies, as well as civil society and the private sector, in the HIV/AIDS response. Also established that year was a multisectoral Governmental Commission on HIV/AIDS as an advisory body to the government for the central coordination of the implementation of the new strategy.

The current national strategy outlines responsibilities across government. Each implementing ministry is required to develop an annual action plan and budget for its HIV/AIDS activities; both the budget and plan must be submitted to the Commission for approval. The following are among the ministries involved (followed by their responsibilities):

- Ministry of Social Affairs (MoSA): HIV prevention, treatment and care among the general population
- Ministry of Education: HIV prevention in schools and among youth; health education
- Ministry of Justice: HIV prevention, treatment and care in prisons
- Ministry of Interior: "prevention of vocational hazards" among police and disaster management agencies
- Ministry of Defense: VCT among army recruits
- Ministry of Population: focus on Russian-speaking youth through the Non-Estonians' Integration Foundation

When the Global Fund program was operating, its CCM was directly responsible for Global Fund implementation and monitoring activities. The CCM was disbanded after the program ended, however, leaving the Governmental Commission on HIV/AIDS as the sole national-level policymaking body. Civil society and the private sector are represented on the Commission (as they were on the CCM).

ART was first provided in 2001 and just 100 people were receiving it in 2003, when the Global Fund program began. An NIHD representative said her "best estimate" was that "700 to 800" people were on ART in April 2008.<sup>10</sup>

<sup>10</sup> Interview with Annike Veimer, director of public health programs at NIHD, in Tallinn (April 21, 2008).

### 3. The Global Fund program in Estonia

The explosion in HIV cases in Estonia occurred at the same time the Global Fund was launched and issued its first calls for proposals. Government officials created a Country Coordinating Mechanism (CCM) and decided to apply for two main reasons: i) they wanted help establishing viable prevention and treatment strategies and programs, and ii) they were concerned about potentially burgeoning HIV-related costs. The original application, prepared in 2002, was quite explicit in laying out the problems and concerns<sup>11</sup>:

*Estonia has the most rapidly spreading HIV epidemic in Europe. The country is responding vigorously but needs significant and immediate external investment if it is to respond as rapidly and effectively as possible. Estonia faces an HIV epidemic spreading at 10 times the rate in most Western European countries, yet has less than a third of the resources available to respond.*

The CCM's proposal, titled "Scaling Up the Response to HIV in Estonia," was approved in the second round of Global Fund grants. The program officially started on October 1, 2003 and ended four years later.<sup>12</sup> The principal recipient of the grant was NIHD, a department within MoSA that was created the year the grant began. More than \$10 million was requested over the grant's lifetime; in the end, a total of \$10.49 million was disbursed through the Global Fund program.

The approved proposal called for the implementation of programs with three main components: prevention work with young people; treatment and care for PLHA; and targeted interventions for high-risk communities such as IDUs, sex workers, prisoners, and men who have sex with men (MSM). In terms of HIV treatment, the key objective was "to improve the quality of life of people living with HIV/AIDS by improving access to social support and health care."<sup>13</sup>

The original application also highlighted the importance of a multi-stakeholder approach that included civil society. The CCM exceeded Global Fund recommendations regarding inclusiveness: half of its members were not from the public sector.

Government officials claimed from the very beginning that the grant was intended primarily to support their financial and programmatic scale-up efforts, not to cover them altogether. According to a recent government report, for example<sup>14</sup>:

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<sup>11</sup> The original application is in PDF format on the Global Fund's website: [Estonia\\_application\\_2ESTH\\_85\\_189\\_full.pdf](#).

<sup>12</sup> Estonia's Global Fund program ran for only four years, one year less than the standard five-year program.

<sup>13</sup> See [Estonia\\_application\\_2ESTH\\_85\\_189\\_full.pdf](#)

<sup>14</sup> From Estonia progress report to UNAIDS, 2008.

[http://data.unaids.org/pub/Report/2008/Estonia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Estonia_2008_country_progress_report_en.pdf).

*The condition for receiving the grant was that the Estonian government [would] not reduce the financing of HIV/AIDS prevention and [would] continue the implementation of the national HIV/AIDS program. Global Fund resources have enabled [the government] to expand considerably the evidence-based interventions and cover the expenses related to the increasing need of ARV drugs.*

Evaluations over the years of Estonia's Global Fund program have been mostly positive. A grant scorecard from June 2005, halfway through the program's term, rated it a "go"<sup>15</sup>—which means that evaluators recommended that all promised funding be disbursed. Of the 30 indicators evaluated, 24 had achieved "100% (or more) of target." Objective 6, which covered ART access and monitoring, received a "very good performance" rating.

That key objective was also examined in a May 2007 performance report.<sup>16</sup> At that time, evaluators said the program had "achieved" its goals to date in terms of "100% reach of ART to those in need." The report did note, however, that one key element of the objective was falling short: the number of uninsured PLHA who receive medical care (health monitoring). That gap, which remains a major challenge more than a year later, highlights stakeholders' ongoing difficulty in identifying HIV-positive people and encouraging them to access health care in general.

As noted in Section 2, the number of people on ART rose significantly over the course of the Global Fund program. In just three years, for example, the total increased from 116 (late 2004) to 721 (September 2007).<sup>17</sup> Of those, nearly three quarters (532 individuals, or 72 percent) were uninsured. The program also supported a major expansion in HIV prevention, including targeted harm reduction interventions for IDUs (see Appendix 2).

Most stakeholders, regardless of sector, express satisfaction with the results of the Global Fund program. According to Igor Sobolev, chairman of the Estonian Network of People Living with HIV (EHPV), a leading NGO sub-recipient, "The Global Fund was vital. It not only ramped up services, but helped create a viable, sustainable civil society. It raised our status and gave us the capacity to be better monitors, evaluators and advocates. Also, the Global Fund helped prompt better integration of health services by removing specialized AIDS centers."<sup>18</sup>

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<sup>15</sup> The scorecard is available in PDF format on the Global Fund website: June2005\_scorecard\_2ESTH\_189\_gsc.pdf.

<sup>16</sup> The performance report is available in PDF format on the Global Fund's website: May2007\_performance\_report\_2ESTH\_189\_gpr.pdf

<sup>17</sup> National Institute of Health Development, "Estonian Program of Global Fund to Fight AIDS, Tuberculosis and Malaria," December 2007.

<sup>18</sup> Interviewed in Tallinn, April 22, 2008.

#### 4. Challenges related to post–Global Fund transition

The Global Fund program undoubtedly had a major impact and influence on the AIDS response in Estonia. However, the program did not occur in a vacuum. All stakeholders agreed from the beginning that it would be devastating from a public health perspective—as well as morally untenable, given the lifeline that had been thrown to hundreds of needy individuals—to eliminate or even scale back the projects and services initiated and expanded with Global Fund support. It was clear that sustaining the vital services, including ART provision, would be necessary after the Global Fund program ended.

In Estonia, the obvious and logical option was for the government to assume responsibility by taking over the Global Fund program and funding it from its national budget. That option is also most likely, and preferable from capacity and continuity perspectives, in other countries—but especially so in Estonia. As noted by the former Global Fund program manager (and current NIHD staffperson), “Estonia is lucky because we’re relatively rich....The government can afford to add new funds to the overall budget to cover program costs and thus does not need to shift funds from elsewhere. Shifting funds would have been much more complicated and difficult because some ministries and officials would have resisted.”<sup>19</sup>

Various Estonian government agencies and departments have subsequently been charged with funding and administering elements of the Global Fund program. In some cases this has entailed folding Global Fund projects into already established programs; in others the assumption of responsibility represents a completely new activity area for a ministry.

Government policymakers have based their decisions and strategies on the National HIV/AIDS Prevention Strategy 2006–2015, the national plan first promulgated in 2005. Even with advance warning, however, the transition—which is properly seen as a multi-year process that began far before the program ended and continues to this day, nearly a year after its end—has not been without challenges, complications, and criticisms.

This section provides an overview of some notable perceptions, developments, and issues related to the transition. Most, but not all, are related to the core issue of this report: access to ART and related HIV treatment services for PLHA. Some were raised by the government itself, others by civil society. Each challenge area is followed by a brief discussion of responses taken (if any), outcomes, and potential meaning for the future.

In some cases, observers and stakeholders disagree on the very facts and history of an issue. It is not possible to state who is right or wrong in such cases. The lack of clarity and differences in perception are themselves instructive, however, because they illustrate how difficult effective collaboration can be among committed stakeholders who represent diverse interests. Such “challenges around challenges” are likely to arise in most other countries and contexts.

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<sup>19</sup> Interview with Annike Veimer, director of public health programs at NIHD, in Tallinn (April 21, 2008).

## 4.1 Funding and budget support

Funding represents the major challenge to Global Fund program sustainability from the government's perspective. It may be true that the government **can** afford to allocate new funds to sustain and expand HIV/AIDS services provided through the program, but it may not always **want** or **choose** to. For one thing, ART provision is already expensive, and will become even more so as more people access treatment. The government's ability to lower procurement costs is limited by EU patent-protection guidelines that all but prohibit the use of lower-priced generic ARVs.

### Funding crisis and successful public appeal

In June 2007, the government announced that, contrary to previous statements, it could not afford to maintain the Global Fund program's level of funding for HIV and AIDS programs. That announcement implied that funding for ART provision would be cut, thereby reducing the number of people with access to the vital medicines.

The government's statement galvanized local civil society. A coalition of NGOs organized a roundtable meeting for their sector's stakeholders and drafted a public appeal, signed by 17 civil society groups, to submit to the government. The effort was international in scope: nearly 100 NGOs from 40 countries joined their Estonian counterparts in urging the government to reverse its decision. The widely circulated appeal called on the government to agree to commit to funding HIV/AIDS prevention and treatment programs at the same level for the first post-Global Fund year, and to recognize the need to increase the budget in subsequent years. (See Appendix 1 for the text of the appeal.)

The civil society sector's efforts were successful. In October 2007, the minister of social affairs agreed to not reduce funding for 2008. Two months later she also signed an agreement stating that a representative from the Estonian Network of People Living with HIV would be appointed to the government's procurement commission. That request had been made by civil society advocates as well.

Although HIV/AIDS funding in the 2008 budget was "saved," similar moves to cut resources are likely to arise again in the future—perhaps even in the run-up to the 2009 budget. In early 2008, Estonia began experiencing a major economic slowdown after nearly 10 years of rapid growth. In late April, the Ministry of Finance said the government had reached agreement "in principle" on spending cuts totaling 3.1 billion kroons (\$310 million) from the state budget. In that announcement, individual ministries were warned that they may each need to cut at least 100 million kroons from their own budgets for that overall amount to be reached.<sup>20</sup>

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<sup>20</sup> BBJ News, "Estonian government reaches accord on budget cuts," April 25, 2008. [www.bbj.hu/news/news\\_38898\\_estonian%2Bgovernment%2Breaches%2Baccord%2Bon%2Bbudget%2Bcuts.html](http://www.bbj.hu/news/news_38898_estonian%2Bgovernment%2Breaches%2Baccord%2Bon%2Bbudget%2Bcuts.html)

Civil society advocates have vowed to resist any cuts to HIV/AIDS programs, and they have an ally in NIHD. As of May 2008, it was unclear as to i) the total spending cuts (if any) the government would require; ii) each ministry's required contribution; or iii) whether changes in funding levels for HIV/AIDS services in 2009 were being considered.

#### Financial requirements for increased ART uptake

Jarno Habicht, the head of WHO's country office in Estonia and a former member of the CCM, stressed the fact that there is "no cap" on the number of people who can eventually be on ART in Estonia.<sup>21</sup> "We expect treatment access to rise to between 2,000 and 3,000" in the next few years, he said, adding:

*It will take a huge financial commitment to afford this. And the expansion has other costs too. For example, there will be a need to increase funding for other services such as case management. Part of the solution is perhaps to get the private sector more involved.*

#### Gap from end of Global Fund program (September 30, 2007) to end of calendar year (December 31, 2007)

Government policies require contracts to be on a calendar-year basis. That meant follow-up contracts for service providers could not officially start until January 1, 2008. In an effort to prevent the suspension of delivery of key services, Global Fund program managers at NIHD decided to reserve some Global Fund monies to cover project costs through the end of 2007, a full three months after the program officially ended.

### **4.2 Government's level and extent of preparation**

#### Civil society perceptions

Some civil society stakeholders interviewed in April 2008 said the government did not adequately prepare for the post-Global Fund transition. According to Igor Sobolev, EHPV's chairman, the main underlying problem has been constant staff turnover within government agencies, a situation that contrasts starkly (and negatively) with relative stability in NGOs. Sobolev said frequent turnover limits institutional knowledge because important information is not retained, thereby lessening key decision-making and problem-solving capacities in the public sector.

Sobolev said one problematic outcome was that government contracts for service providers were not ready by October 2007, when the Global Fund grant ended. He claimed NIHD had previously given his NGO and others only an "informal" explanation as to what the process would entail, neglecting to formally disclose information regarding agreements and contracts. Therefore, he said, "We didn't know until January 2008 what

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<sup>21</sup> Interviewed in Tallinn, April 21, 2008.

we'd have for the 2008 calendar year. We didn't know what the conditions would be. We didn't know what the rules would be. It was a mess.”<sup>22</sup>

Other civil society staff interviewed in April 2008 did not share Sobolev's view. Tatjana Magerova, the director of a harm reduction NGO in Narva, said she had been mostly pleased with the post-Global Fund transition. “I was very well informed during lead up and preparation to transition,” she said.<sup>23</sup> “From the very beginning, [NIHD] said civil society would always continue to be funded after the Global Fund program ended, and I had no reason not to believe them.” Magerova said she had met with NIHD personnel four months before the program ended, and was told then that her organization would be funded in 2008.<sup>24</sup> Another NGO implementer, Irina Moroz from Life Is Going On (LIGO), concurred with Magerova. Moroz said she knew well in advance of the transition period that funding would continue, and at current levels, for her organization's work.<sup>25</sup>

### Public-sector perspective

Annik Veimer, the former Global Fund program manager, said that both she and other government agencies took sufficient steps to ensure a relatively smooth transfer. She noted, for example, that the government had decided to pick up the full cost of procuring ARVs by 2006, one year before the Global Fund program ended. Previously the Global Fund and the government had shared procurement responsibility. Government authorities made that decision because they wanted to be absolutely certain they had the necessary capacity and expertise to oversee all aspects of procurement.

The WHO's Habicht said he also believed the Estonian government had prepared adequately for the transition—and had adequately informed its civil society partners. He noted that the Governmental Commission on HIV/AIDS was established in 2005, a full two years before the Global Fund program ended (see Box A). One primary objective of that Commission, he said, was to replace the CCM as the main multisectoral HIV/AIDS policy body in Estonia. The Commission always has included civil society representatives, he said, as did the CCM.

Habicht said that flow charts outlining government ministries' responsibilities vis-à-vis HIV/AIDS services had been prepared well in advance of the transition and distributed to civil society partners. Those flow charts made it clear, he said, that a cross-government structure had been devised, with different ministries assigned different responsibilities.

According to Habicht, the root of the problem was that some civil society groups never truly understood the new post-Global Fund structure even after it was explained to them

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<sup>22</sup> Interviewed in Tallinn, April 22, 2008.

<sup>23</sup> Interviewed in Tallinn, April 22, 2008.

<sup>24</sup> Magerova said she mostly “got what she wanted” in the first contract she signed with NIHD for post-Global Fund services. She added that if other organizations are complaining, “I think it's probably their fault for not having done appropriate and extensive background work” as the transition date was approaching.

<sup>25</sup> Interviewed in Tallinn, April 25, 2008.



prior to the transition. Moreover, he said, they opposed nearly all proposed changes—even those that were clearly beneficial for sustainability because they would have helped build capacity in advance.

Habicht, a member of the CCM, gave the following example. He said that in the wake of the Global Fund’s mid-term review (in 2005), several CCM members had proposed having ministries begin gradually taking responsibility for program management prior to the official end. He said that proposal was opposed by civil society representatives on the CCM. The reason for opposition from the NGOs, he said, was that they were used to signing one contract only (with the Global Fund). They did not want to face what they perceived as the unnecessary hassle of dealing with different ministries depending on what services they provided. Habicht added that the NGOs’ preferred option—to not allow ministries to assume responsibilities in advance—was also favored by some ministry officials, who did not want to assume responsibility for HIV/AIDS programs or allocate funds earlier than anticipated.

Ultimately the civil society contingent prevailed and the proposal was voted down by the CCM. In Habicht’s view, the decision to not transfer some Global Fund oversight and funding responsibilities in advance was a lost opportunity to build critical capacity within the public sector.

#### **4.3. Lack of consistency and coordination among government agencies regarding HIV/AIDS service responsibilities**

As noted previously, HIV/AIDS programs and services that were once organized under one system (the Global Fund) are now the responsibility of different government agencies (see Box A). Since taking over, however, the agencies have operated at different levels of efficiency and effectiveness. They also do not follow the same procedures and strategies in everything from contracts to implementation oversight, even though the National HIV/AIDS Prevention Strategy 2006–2015, which sets broad guidelines for all stakeholders to follow, is supposed to ensure consistency. Stakeholders from across the spectrum agree that this ongoing challenge is particularly frustrating and problematic.

##### Support commitments

The Ministry of Social Affairs has given written commitments to all its service-delivery partners, most of which are NGOs, that it will support their work for five years. Separate agreements must be signed annually to determine specific funding levels and service priorities, but civil society partners are nonetheless extremely pleased with the longer-term guarantees. They help reduce the usually persistent pressure on implementers regarding how (or if) to plan for more than just the short term. Many NGOs view such developments as greatly improving their ability to provide better and more effective services because they are less distracted by concerns over sustainability.

Other agencies, including the Ministries of Justice and Education, have not extended such commitments to implementing partners.

### Lingering gap in school-based HIV education

The Ministry of Education has responsibility for crucial HIV prevention and education projects in the country's schools. Ministry officials decided to discontinue a Global Fund-supported program in which specially trained adult HIV educators visited schools and discussed HIV, STIs and other health issues with students directly. Officials said they preferred to incorporate such information and education directly into a new national curriculum. Regardless of the ultimate merits of their plan, the fact remains that they stopped what by all respects was a useful and important initiative before the new curriculum was ready. As of April 2008, school-based HIV education programs had not been provided for several months. The ministry reportedly has resisted entreaties to reinstate the specially trained educators even on an interim basis, at least until the new curriculum is available. It claims it does not have the funds to pay the specialists for even just a few months.

The education ministry has been criticized repeatedly for being short-sighted and risking the health of Estonian students. From the government side, Merilin Mäesalu, a chief specialist in MoSA's Public Health Department, accused the Ministry of Education of being "the main bottleneck" to an effective post-Global Fund transition. She said, "We say that we can't wait. We must solve this problem. We're trying to do so by convincing them that it is important to fill the continuing gap."<sup>26</sup>

On the civil society side, Nelli Kallikova from the AIDS Support Center said the ministry's actions are particularly outrageous because the HIV epidemic is generalizing, and that school-age girls greatly need improved and consistent access to HIV prevention education. She said, "We're seeing that young women and girls comprise larger shares of new cases. Now, for example, more women than men between the ages of 15 and 19 are HIV-positive."<sup>27</sup>

The ESPO Society's Slava Vassiljev, one of the civil society representatives on the national AIDS commission, said that representatives from both the Ministries of Education and Justice—which also has been criticized for its slow pace in implementing its new HIV-related responsibilities—had faced tough questions during a recent commission meeting. "Unfortunately," he said, "mid-level bureaucrats hemmed and hawed, and didn't really have satisfactory responses as to why they were not moving forward more appropriately and aggressively."<sup>28</sup>

MoSA's Mäesalu added that it appeared the Ministry of Justice at least was recognizing the problem.<sup>29</sup> She said the agency had recently hired a new contact person on HIV/AIDS, a development that raised hopes of more rapid and comprehensive implementation of the ministry's responsibilities.

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<sup>26</sup> Interviewed in Tallinn, April 22, 2008.

<sup>27</sup> Interviewed in Tallinn, April 21, 2008.

<sup>28</sup> Interviewed in Tallinn, April 25, 2008.

<sup>29</sup> Interviewed in Tallinn, April 22, 2008.

#### **4.4 Restrictive contracts**

A representative from Convictus Eesti, an NGO that has worked extensively in prisons over the past several years, reported that he and his organization were upset by various restrictions added to its first post-Global Fund contract, which it signed with the Ministry of Justice.

Latsin Alijev said he was initially “pleasantly surprised” because the new contract allocates a bit more money than the NGO had received through the Global Fund program.<sup>30</sup> He added, though, that it contains language specifically stating that the ministry can “change the agreement” at any time, and for any reason. That raises the possibility that the ministry could arbitrarily, and suddenly, decrease funding or even alter terms if authorities are displeased.

Alijev also said he and his colleagues were concerned because the new agreement does not mention several services that Convictus Eesti had long provided, such as hosting “information days” in prisons during which outside experts discussed health issues such as TB and hepatitis. The result is that the organization is now effectively limited to one major activity, organizing support groups for HIV-positive inmates.

In Alijev’s view, the new restrictions indicate that ministry authorities “don’t understand the importance of our work.” He said the organization was trying to improve the situation with the help of NIHD, which as Global Fund PR had supported a wide range of prison-based services.

#### **4.5 Civil society’s effectiveness and relations with the government**

Relations between the government and civil society appear to have been mostly collegial in recent years, but tensions do exist. The transition process from the Global Fund to the national budget has exacerbated some of those tensions and created new ones. In general, many public-sector respondents consider civil society to be ineffective and misguided. In return, some civil society respondents claim they are not properly respected by government or given adequate credit for the success of their direct service delivery.

##### Government perspective

According to Habicht from WHO, the civil society sector is not as effective as it should be in helping shape the overall HIV/AIDS response. He said their “voices have not been heard” to the fullest extent because they lack adequate human capacity, are poorly informed in some key areas, and “miss the big picture” when they focus primarily on specific issues.<sup>31</sup>

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<sup>30</sup> Interviewed in Tallinn, April 22, 2008.

<sup>31</sup> Interviewed in Tallinn, April 22, 2008.

He cited as an example some NGOs' persistent claim that the Estonian ARV procurement process is not transparent. Habicht said that claim is easily refuted because "all the procurement information is available online."

In general, he said, civil society groups would be better advocates if they understood how government functions. That would improve their ability to identify when compromise is the most appropriate response and when they might successfully push harder.

Habicht's observations were similar to those reported by the authors of the WHO evaluation report published in April 2008:

*The capacity of service-providing NGOs to manage projects has improved significantly...[but] NGOs have made less progress in developing some of the other skills needed for a strong and vibrant third sector in Estonia. Examples of such skills include: contract negotiation, risk analysis and management, public fundraising, reserves planning and development, resource management and planning, human resource management, and advocacy.*

*...[T]here are some advocacy and lobbying areas where NGOs have been extremely successful, e.g., in securing financial resources from the state budget following the end of the Global Fund grant. However, this could be developed further and made more systematic, by recognizing the collective strength of NGOs acting together, e.g., through a network focused on HIV and AIDS. There is still evidence of dependency in this area with, for example, some respondents saying that they could do nothing about the issue of opioid substitution therapy in arrest houses unless something came 'from the top.' Although there is an element of truth in this, in that policy change is likely to require joint ministerial action across the Ministries of Social Affairs, Justice and Interior, NGOs are well-placed to influence such action through lobbying and advocacy efforts.<sup>32</sup>*

### Civil society perspective

Some civil society representatives acknowledge that the sector in general may not be as effective as it could be. Igor Sobolev, EHPV's chairman, said he believes the main problem is that civil society is rarely united<sup>33</sup>—with the successful joint advocacy effort in the summer of 2007, to guarantee continued national budget funding, being the exception that proves the rule.

He added, though, that some important external barriers still exist that prevent civil society from achieving its full potential. In his opinion, for example, civil society is

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<sup>32</sup> World Health Organization, "Evaluation of Fighting HIV/AIDS in Estonia", April 2008. Online in PDF format: [www.euro.who.int/Document/E91264.pdf](http://www.euro.who.int/Document/E91264.pdf).

<sup>33</sup> Interviewed in Tallinn, April 21, 2008.

underrepresented on the Governmental Commission on HIV/AIDS, especially in comparison with the now-defunct Global Fund CCM.

Sobolev also said that government officials far too rarely address the language issue in a meaningful way. A significant number of representatives of HIV/AIDS NGOs are Russian-speakers, which is not surprising given the epidemic's disproportionate impact on members of the Russian-speaking minority. However, government policies mandate that most meetings be held exclusively, or nearly exclusively, in Estonian. That limits the ability of non-Estonian advocates to participate.

#### **Box B**

##### **ONE NGO PROVIDER'S ACCOUNT OF TRANSITION TO NATIONAL BUDGET**

Most Estonian NGOs that served as sub-recipients of the Global Fund program have subsequently been supported for similar services through the national budget. Nelli Kallikova, the director of the AIDS Support Center, a harm reduction NGO in Tallinn, summarized some transition-related issues for her organization as follows:

**Process:** “Last summer [prior to the official end of the Global Fund program], we were invited to submit an application for continued funding to the Ministry of Social Affairs. We were approved for the same amount (for one year) as in our last Global Fund contract. We didn’t ask for additional funds at the time for two reasons. For one thing, we were uncertain as to whether doing so would damage our chances of getting a new contract. Also, I realized that additional funds would lead to additional services, and that I would need more staff to provide them. That would be complicated, at least in the short term, because it can take a long time to train people.”

**Number of clients:** “The number of clients hasn’t changed. For example, we used Global Fund money to put 120 people on methadone....and we’re still able to provide that service to the same number of people, funded through the national budget.”

**Guarantee of support.** “Until this year, all of our contracts [through the Global Fund] were for just one year only. That made things difficult in many ways because it’s hard to plan for the longer-term, especially when the bulk of funding is from that one source. Now, though, NIHD [the National Institute of Health Development] has formally committed to supporting us for five years. We don’t know the exact amount we’ll receive each year—and we still need to apply for specific funding on an annual basis—but we do have a guarantee of support for five years in writing. This is good development for us and an important expression of good will. Other public-sector funders have copied NIHD’s strategy. For example, we also received a formal guarantee of five years’ support from the city government, which gives us some funds as well.

#### **4.6 Care and services for prisoners**

At any given time, HIV prevalence among prisoners in Estonia is several times higher than among the general population. That is not unexpected in light of two linked facts—that IDUs continue to comprise the majority of all the nation’s HIV cases and that drug

users are incarcerated far more commonly than any other group. Veimer estimated in April 2008 that about 500 of the nation's 4,000 prisoners were HIV-positive, which constitutes more than 12 percent of the total inmate population.<sup>34</sup>

Government and civil society sources listed several challenges in providing comprehensive and effective HIV treatment and prevention services to inmates. The major one is that all prison-related services, including health care, are the responsibility of the Ministry of Justice. It is required to comply with national treatment guidelines and standards in its parallel health system; however, observers contend that the overall level of care lags behind what is available outside.

ART access does not appear to be a problem. More than 100 inmates were on ART, according to Veimer, in April 2008—which means that prisoners comprise nearly 20 percent of people receiving ART across the country. However, the ministry's policies and record regarding HIV prevention are patchier. It allows NGOs to distribute condoms to inmates, but bars the provision of clean needles and syringes within its facilities.<sup>35</sup> Veimer said that access to methadone for substitution treatment purposes has been inconsistent, varying not only among different facilities but within individual ones as well. She said she had heard reports of inmates receiving methadone for several weeks and then suddenly being denied access for no apparent reason.<sup>36</sup>

Yet another challenge is that the Ministry of Internal Affairs also has certain criminal justice responsibilities, notably its oversight of pre-trial detention. ART is available to individuals awaiting trial, but methadone and other harm reduction services are not. The lack of coordination and consistency among different agencies is dangerous to detainees' individual health and well-being and can have even greater public health consequences in terms the overall HIV epidemic.

#### **4.7 Lack of generic ARVs**

As noted previously, increasing ART uptake will have serious financial consequences for the national budget. This challenge is much greater in Estonia than in many other countries, including some with higher disease burden, because only brand-name ARVs are currently available in the country.

A data review conducted in early 2008 showed wide variations in ARV purchase prices,<sup>37</sup> from the equivalent of \$746.52 per patient per year for Merck's Stocrin (efavirenz) to \$11,083.92 per patient per year for Gilead's Truvada (emtricitabine + tenofovir). Prices paid by the Estonian government for other ARV products commonly

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<sup>34</sup> Interviewed in Tallinn, April 21, 2008.

<sup>35</sup> Latsin Alijev from Convictus Eesti, an NGO that provides HIV-related services in prisons, said he sees little indication that the Ministry of Justice will change this policy in the near future. Ministry officials regularly point to a national law explicitly forbidding the use of alcohol and drugs in prisons; inmates often get longer sentences if found to be intoxicated. Interviewed in Tallinn, April 22, 2008.

<sup>36</sup> Interviewed in Tallinn, April 21, 2008.

<sup>37</sup> The specific information regarding ARV prices in Estonia was provided to the author in April 2008 by members of a research team conducting a regional review of ARV pricing and access.

used worldwide included \$3,550.44 per person per year for GlaxoSmithKline's Combivir (zidovudine + lamivudine) and \$7,195.44 for Abbott's Kaletra (lopinavir/ritonavir).

About 85 percent of patients currently on ART in Estonia are on one of two regimens. Assuming Combivir is used, the cost to the government per patient per year for those regimens is as follows (not including sales tax):

- Combivir (zidovudine + lamivudine) + Stocrin (efavirenz) = \$4,296.96
- Combivir (zidovudine + lamivudine) + Kaletra (lopinavir/ritonavir) = \$10,745.88

It is not difficult to see how such prices can cause concern among budget managers. It is also true that generic versions of all ARVs provided in Estonia are used in other parts of the world; such versions can be as much as 90 percent cheaper.

In theory at least, Estonia could follow the lead of many other countries, including Thailand, Brazil, and South Africa, and take more aggressive—but perfectly legal, as per the World Trade Organization (WTO)—steps to lower its ARV purchasing costs. For example, Estonian law specifically allows the use of parallel importation, one so-called flexibility that WTO signatories are permitted to exercise to lower the cost of ARVs and other essential medicines.<sup>38</sup>

As of April 2008, however, the government had not exercised that legal right in regards to ARVs. Among other things, Estonian authorities are constrained by relatively rigid EU patent-protection policies. According to the WHO's Jarno Habicht, the Estonian government is not willing to risk antagonizing other EU members by seeking to utilize TRIPS flexibilities to lower ARV costs. In their view, he said, Estonia is “not big enough” to declare a public health emergency<sup>39</sup>—a TRIPS-permitted step under which other countries have justified strategies to procure lower-priced ARVs.

Habicht said that few other options are immediately available, noting that the drug companies are not likely to lower prices voluntarily when there is no pressure for them to do so.

Unlike in many other countries, local NGOs and PLHA in Estonia have not made access to generic ARVs a major advocacy priority. That stems from a persistent belief that generic medicines are less effective and not as safe as brand-name drugs, even among individuals who have worked on HIV treatment and prevention issues for many years. The comments of one HIV-positive leader of an HIV/AIDS NGO illustrate the mindset: “Thank God no generics! We think that brands mean quality. We are afraid to use or consider using drugs from places like India.”<sup>40</sup>

#### **4.8 Problem and priority areas in regards to services scale-up**

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<sup>38</sup> Parallel importation and other “flexibilities” are outlined in the WTO's Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement.

<sup>39</sup> Interviewed in Tallinn, April 21, 2008.

<sup>40</sup> Interview with Slava Vassiljev from ESPO Society in Tallinn, April 25, 2008.

There is nearly universal agreement that the Global Fund program greatly improved Estonia's HIV/AIDS response. Numerous challenges nevertheless remain. For one thing, much more needs to be done in certain key prevention and treatment areas that have long been priorities; at the same time, the rapidly changing nature of the epidemic means new priorities are regularly identified and demand attention.

### HIV testing

Annik Veimer from NIHD said in April 2008 that a total of six public-sector VCT sites were operational.<sup>41</sup> Express tests have only just become available, she added, and the department hoped to make them available at all sites by the end of the year. Scaling up the availability of express tests should, in her opinion, increase testing uptake because it will be far less likely that patients will choose not to learn their test results.

### HIV-related stigma and discrimination

All respondents agreed that HIV-related stigma and discrimination remain major barriers to uptake of care and treatment services among those living with HIV and members of vulnerable populations. Veimer said she believed stigma was lessening, however, at least in part because of the expanded availability of ART. Other important steps, she said, included recent media awareness campaigns and the increasing number of private companies that hold HIV/AIDS training seminars for employees.

Veimer gave a specific example illustrating the lingering effect of stigmatizing attitudes among many Estonians.<sup>42</sup> In recent years, she said, a handful of communities have resisted low-threshold facilities serving IDUs. In July 2006, members of one neighborhood in Tallinn filed suit in court to stop the city from establishing such a facility in their community. A settlement was finally reached a year later; although on-site needle and syringe exchange was banned, the site's organizers are permitted to provide mobile-based exchange services. (Veimer added that she and her colleagues were pleased that no legal precedent was created for closing down such services in general.)

### Far too many HIV-positive individuals are not aware of their status

As a result, they are not receiving adequate medical care, including ART, or potentially useful social support. Veimer said the most persistent challenge is that people "present too late for care...often when they are already clinically ill with AIDS."<sup>43</sup> She said the reasons for their delays vary, but she believed that most either do not know about existing services or are afraid to access them because of stigma and confidentiality concerns. The first reason points to the need for more comprehensive outreach and awareness efforts, especially among members of vulnerable populations, and the second reinforces the need for improved anti-stigma activities.

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<sup>41</sup> Interviewed in Tallinn, April 21, 2008.

<sup>42</sup> Interviewed in Tallinn, April 21, 2008.

<sup>43</sup> Interviewed in Tallinn, April 21, 2008.



Both government and civil society informants agree that substandard healthcare uptake among HIV-positive IDUs represents the biggest current problem in this regard. A recent WHO evaluation of Estonia's HIV/AIDS response concluded the following:

*Coverage of ART among HIV-positive IDUs appears to be low. For example, although the vast majority of all HIV infections in Estonia have been among IDUs, only 30 to 35 percent of those receiving ART in Narva are reported to be IDUs. The problem does not seem to relate to access to HIV testing. Coverage of HIV testing among IDUs appears to be good. For example, in 2005, more than two thirds of IDUs (68 percent) reported having had an HIV test in the last year. However, relatively few of these then attend for medical services.*<sup>44</sup>

### Limited case management

Both Veimer and Merilin Mäesalu (from MoSA) highlighted the lack of a viable case management system in Estonia. What this means in practice is that, for example, continuity of care for HIV-positive individuals and people on substitution treatment rarely exists when they move in and out of prison. Such an omission can have severe health impacts, especially if ART access and adherence are affected. Discontinuation of access to substitution treatment greatly increases the possibility that a client will revert to injecting drugs and face all the attendant health risks such behavior entails.

Improved case management could also prove beneficial to IDUs, who often fall through the cracks in terms of comprehensive and affordable care. Many, if not most, do not have health insurance. Moreover, as noted in a recent WHO evaluation, they are likely to “require a range of services, e.g. ART, TB and STI treatment and opioid substitution therapy [substitution treatment], which are still provided in an isolated way by different organizations in different places.”<sup>45</sup>

According to Mäesalu, MoSA policymakers are currently developing a case management system that will be fully launched over the next two years.<sup>46</sup>

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<sup>44</sup> World Health Organization, “Evaluation of Fighting HIV/AIDS in Estonia”, April 2008. Online in PDF format: [www.euro.who.int/Document/E91264.pdf](http://www.euro.who.int/Document/E91264.pdf).

<sup>45</sup> World Health Organization, “Evaluation of Fighting HIV/AIDS in Estonia”, April 2008. Online in PDF format: [www.euro.who.int/Document/E91264.pdf](http://www.euro.who.int/Document/E91264.pdf).

<sup>46</sup> Interviewed in Tallinn, April 22, 2008.

## 5. Lessons learned and recommendations

The ongoing challenges related to the post–Global Fund transition, summarized in Section 4, should not obscure the fact that ART access continues to increase in Estonia. So too does access to other crucial HIV/AIDS services provided by the government and its civil society partners.

The process has not been easy or smooth, however. Significant obstacles remain as well, most notably in regards to:

- ensuring stability and increases in budget support;
- increasing uptake of ART and other HIV treatment services, especially among IDUs;
- improving coordination among—and the quality and scope of services provided by—all government ministries; and
- improving communication between civil society and government in order to reduce misconceptions and clarify policies and strategies.

Much of what has been done (and still must be done) in Estonia is context-specific. That is especially true in light of the country’s relative wealth, small absolute number of HIV cases, and drug use–driven epidemic. That said, Global Fund programs will one day end or decline in importance even in relatively poor countries with millions of PLHA who contracted HIV through heterosexual sex. Some of the most basic lessons learned from recent developments in Estonia are likely to be relevant there as well

The following is a hybrid list of lessons learned and recommendations. Some are general and others specific; each, though, is designed to improve access to HIV/AIDS services for those in need. That overarching objective should be the basis of decisions made and policies adopted throughout the world.

The recommendations are aimed primarily at governments because of the public sector’s leading role in designing, implementing and sustaining Global Fund programs.

1. **One national strategy should be developed and approved at least a year in advance of an impending post–Global Fund transition.** All stakeholders from across the government and civil society should be invited to participate in the development of this single, comprehensive strategy. If they are excluded, they may not understand or accept it; as a result, the quality of service provision could suffer, as could cooperation and coordination.
2. **All stakeholders (and especially the government) should recognize the long-term nature of their commitment.** When HIV/AIDS strategic plans stretch over several years—Estonia’s current one extends for 10 years, for example—it is easier to lock in resources and engender ongoing financial, social, and political support. Certainly plans can be altered if needed, but the overall frameworks of a long-term strategic plan should remain solid.

3. **Start planning for the end of the Global Fund program on the day it begins.** It may seem as though Global Fund assistance will always be available. After all, most individual programs last five years, and often multiple programs may be operating in one country on an overlapping basis. There are no guarantees, however, especially with the Global Fund dependent on support from wealthier nations whose political and economic situations fluctuate regularly.

Policymakers in-country should develop plans in preparation for the end of each individual Global Fund program. In doing so, they should consider ways to maintain and expand funding for Global Fund–initiated projects and services and to continue capacity-building initiatives. Many countries, particularly those with high disease burdens and limited resources, might find replacement donor support to be the most affordable and appropriate option; if so, they should begin negotiating with bilateral donors and/or multilateral institutions from day one of the Global Fund program. Special grants and loans from those sources could be secured to cover the costs of sustaining and expanding Global Fund programs once they officially end.

4. **A transparent and effective M&E (monitoring and evaluation) structure should be created at the national level.** It is absolutely vital for all policymakers and stakeholders to know where HIV/AIDS funds are going, who or what is using them, how they are used, and whether they have been effective in achieving pre-determined goals. Public trust in and support for HIV/AIDS programs will decline if M&E is substandard or opaque (or both). Even the appearance of corruption is unacceptable. Regular audits should be conducted and reviewed by independent sources and then made available for public scrutiny, i.e., on government websites.
5. **Some flexibility should be built into transition plans so as to ensure cooperation, coordination, and consistent service delivery.** In Estonia, for example, the government agreed to allocate funds to cover a three-month gap between the official end of the Global Fund program and the beginning of the fiscal year. This eliminated the possibility that service providers would need to suspend activities for those in need. Similarly, NIHD offered its NGO partners formal cooperation agreements extending over five years. That gesture was greatly appreciated because it signified the government’s trust in its partners’ activities and assured medium-term sustainability.
6. **Officials in all government agencies, including finance ministers and trade and health policymakers, should be made aware of the economic and social benefits to societies overall of comprehensive HIV/AIDS programs.** Countries are wealthier, more productive and more hopeful when all in need have access to ART and other life-prolonging and health-maintaining medicines. Making HIV/AIDS services a key budget priority is not money wasted or better used elsewhere.

7. **More aggressive and targeted advocacy should be directed at key multilateral institutions that focus extensively on reduced public spending.** Maintaining and expanding HIV/AIDS programs requires vast amounts of public spending. In some countries, however, agreements with the World Bank and International Monetary Fund mandate reductions in public expenditures, including for the health sector. With the support of international and local civil society advocates, government officials (especially finance ministers) should step up and maintain pressure on such institutions to relax the public-sector spending caps that are conditions of loans and other economic plans implemented with the aid of these organizations. Public spending cannot and should not be reduced during health crises; instead, ways should be explored to expand it.
8. **Government policymakers should be as open as possible to strategies and policies used elsewhere to respond to HIV epidemics.** For example, in recent years Estonia has accepted and embraced harm reduction as a core HIV prevention strategy. Health officials were initially hesitant, but changed their minds after carefully reviewing scientific evidence about and projects providing needle exchange and substitution treatment. Such initiatives are now integral parts of the country's HIV prevention efforts.
9. **Government officials and civil society partners should always seek ways to increase availability of generic drugs.** Some countries have been quite successful in using global trade policies and rules to dramatically reduce the cost of ARVs and other essential medicines. In most cases, the reductions have occurred either because generic drugs actually have been introduced or because manufacturers of brand-name drugs lower prices because they believe there is a real likelihood of their introduction.

In Estonia, meanwhile, the government continues to purchase only brand-name ARVs at premium prices. It is lucky it can afford such outlays at the moment, but sustainability could be threatened as more and more people receive ART. The government, in concert with civil society, should be much more aggressive in directly challenging EU policies that greatly limit member-states' ability to lower such crucial healthcare costs. For example, one of the specific commitments of the 2007 Bremen Declaration was for European nations to "cooperate to ensure access to affordable medication."<sup>47</sup> Rigid patent-protection policies and limitations on generic medicines seem to violate both the letter and spirit of that commitment. After all, it would seem that improving access to generics would be one of the easiest ways for members to ensure access to affordable medicines.

10. **Meanwhile, health authorities, in partnership with civil society, should initiate awareness and education campaigns about generic ARVs.** This

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<sup>47</sup> The Bremen Declaration on Responsibility and Partnership—Together Against HIV/AIDS was agreed to in March 2007. Those gathered included the 'Ministers and representatives of Governments from the European Union and neighbouring countries responsible for health'. More information is available online in PDF format: [www.eu2007.de/en/News/download\\_docs/Maerz/0312-BSGV/070Bremen.pdf](http://www.eu2007.de/en/News/download_docs/Maerz/0312-BSGV/070Bremen.pdf).

recommendation is relevant in countries such as Estonia where many PLHA and/or healthcare personnel remain suspicious about the quality and effectiveness of generic ARVs in general. Their suspicions are not based on fact, however: generic ARVs are used regularly and safely around the world.

The government's efforts in this behalf are only likely to be successful if it can demonstrate that its drug-regulatory practices and policies are sound. This may require inviting monitors from WHO and other respected international entities to conduct thorough reviews on a regular basis and to issue appropriate reports as to national authorities' ability to ensure uniform quality of all medicines, both brand-names and generics. Such a step would greatly increase the potential success of awareness and education campaigns regarding the use of generics.

Equally important is the fact that generics are far less expensive than their brand-name counterparts. The campaigns should stress the fact that if generics were available, more people could be put on ART for the same amount of money. This would reduce pressure on the national budget and help ensure sustainability of HIV treatment programs.

## **Appendix 1. Civil society's 2007 public appeal on HIV/AIDS funding allocations**

In June 2007, the government announced that it could not afford to maintain the Global Fund program's level of funding for HIV/AIDS programs. That announcement implied that funding for ART provision would be cut, thereby reducing the number of people with access to the vital medicines.

In response, a coalition of 17 Estonian NGOs drafted a public appeal and submitted it to the government.<sup>48</sup> Representatives from some 100 civil society groups in 35 other countries signed a separate document supporting their Estonian counterparts' initiative.

Their efforts were successful. In October 2007, the Minister of Social Affairs announced that overall funding for HIV/AIDS programs in the 2008 budget, which began in January 2008, would not be reduced. The coordinated action by civil society groups was an important step toward re-asserting their vital role as partners with government in the post-Global Fund era.

The text of the Estonian civil society groups' public appeal is reprinted verbatim below (translated into English):

### **From the organizations struggling against HIV and AIDS and communities of people living with HIV.**

**PUBLIC APPEAL:** On the 20th June 2007 an article appeared in the media concerning the Estonian government's plans to reduce the funding allocations for 2008 for the care, treatment and support of people living with HIV and AIDS. The result of this action would be to reduce the commitment to HIV services up to seven times less than had been previously planned. It was said that the resources should be allotted to other social areas such as children's homes, disability services and emergency workers.

Participants of the NGO advocacy seminar, where different organizations struggling against HIV/AIDS took part, agreed to address a public appeal to the state and political leaders, and to appeal to all organizations and individuals who are concerned about HIV/AIDS, who do realize how many lives we will lose through decisions that are ill-advised, fail to recognize the danger to society from HIV and AIDS and pay too little attention to the experience of other countries in responding to HIV and AIDS.

The reduction of money resources for treatment leaves hundred of young people to the mercy of fate and insouciant contrasting of different social groups, who need social help, and only intensifies the present stigma and discrimination of living with HIV.

We would like to remind the government of some facts:

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<sup>48</sup> See

[www.worldaidscampaign.info/index.php/en/campaigns/in\\_country\\_campaigns/europe/estonia\\_a\\_budget\\_freeze\\_aimed\\_at\\_social\\_needs\\_for\\_2008](http://www.worldaidscampaign.info/index.php/en/campaigns/in_country_campaigns/europe/estonia_a_budget_freeze_aimed_at_social_needs_for_2008).

- The strategy has been approved by the government concerning the fight against HIV/AIDS for the years of 2006–2015, and the state operation program of the strategy above for 200–2009 [sic], that is why the full responsibility for financing the program rests with the state.
- During the Special Session of the General Assembly of the United Nations Organizations on HIV/AIDS in 2001 Estonia together with the other members of UNO approved the Declaration concerning the adherence to the struggle with HIV/AIDS, under which access to treatment must be guaranteed. Everyone has a right to treatment.
- The Minister of Social Affairs gave a promise on February 23, 2007 to the representative of the Global Fund, which is involved in the response to fight the diseases of HIV/AIDS, tuberculosis and malaria, to continue financing treatment at the same level, once the Global Fund stops its financing.

Continuous treatment is not only a requirement for the effective management of HIV and AIDS, it also improves the quality of lives for people living with HIV and gives them an opportunity to be a full member of the community and a tax-payer. Continuous treatment prevents the possibility of the appearance of the resistant forms of the virus and its spread.

This disease that especially affects our young people threatens our future state, population growth and national security. The qualitative, consistent and preventive work gives an opportunity to secure people from the further spreading of the virus and our nation's downfall.

Estonia, as a member of the European Union with the highest number of new detected infections, is not entitled to abandon its responsibilities to realize and to expand the preventive work and to secure anti-virus treatment to all indigent people living with HIV-AIDS.

The reduction of financing now will lead to repeated and increased expenses from all parts of the community in the future.

## **Appendix 2. Key HIV prevention challenge: Lagging uptake and access to substitution treatment**

Given that Estonia's HIV epidemic is largely drug use-related, it is not surprising that one of the six main objectives of the Global Fund program centered on HIV prevention and care services for injecting drug users (IDUs). The harm reduction philosophy greatly influenced interventions, which included syringe and needle distribution and ramping up substitution treatment. Over the program's four years, nearly 4.5 million syringes were distributed to IDUs; nearly 11,000 new clients visited needle/syringe exchange sites; and some 4,400 clients were officially registered in exchange programs<sup>49</sup>.

Not all of the targets were met, however, even though the volume of services increased substantially. In terms of needle and syringe provision, at least 80 percent of each target indicator was met (and some even exceeded plans). The program lagged more significantly in regards to substitution treatment: by the end of the program, a total of 654 IDUs were receiving methadone in Estonia, which represented 78 percent of the target (840 people)<sup>50</sup>.

That failure highlights a major challenge in HIV/AIDS service delivery for both the government and its civil society partners. The government has committed to increasing access to harm reduction services in the post-Global Fund era, and policymakers recognize that successful HIV prevention efforts require greatly increased uptake of substitution treatment.

According to Annike Veimer, director of public health programs at the National Institute of Health Development (NIHD), there were an estimated 14,000 IDUs in Estonia in April 2008<sup>51</sup>. "We should have at least 4,000 of them on substitution treatment" to meet WHO recommendations, she said, but only "about 750" were receiving methadone<sup>52</sup>.

Veimer said one reason for the low uptake was that members of the Russian-speaking population, who comprise the majority of IDUs, were "distrustful" of methadone. "They hear bad things about it in the Russia-based media," she said. (Methadone is banned for any purpose in Russia.) Another issue she cited is that "maybe 50 percent" of IDUs now inject ephedrine-based compounds (such as amphetamines) instead of or in addition to opiates. Methadone and similar medicines used in substitution treatment are effective only against opiates.

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<sup>49</sup> National Institute of Health Development, "Estonian Program of Global Fund to Fight AIDS, Tuberculosis and Malaria". Evaluation published December 2007.

<sup>50</sup> National Institute of Health Development, "Estonian Program of Global Fund to Fight AIDS, Tuberculosis and Malaria". Evaluation published December 2007.

<sup>51</sup> All comments attributed to Veimer in this section were obtained during an interview in Tallinn on April 21, 2008.

<sup>52</sup> Of those 750, about 605 were receiving methadone through the state budget, according to Veimer. The rest were enrolled in private clinics.



Veimer acknowledged that the third reason had more to do with limited public-sector capacity to treat drug dependence. She said, “At the end of the Soviet era, we abolished narcological centers because we didn’t like that model. But we didn’t replace them with anything.” As a result, she said, drug-treatment options (including detoxification and rehabilitation) are limited in Estonia.

The capacity limitation issue was echoed by the director of one of the few harm reduction NGOs in Estonia. According to Nelli Kallikova of the AIDS Support Center, “Even though there are 4,000 IDUs in Tallinn, there are less than 300 [substitution treatment] slots. I believe it’s criminal that we promise methadone and then can’t deliver” to those who want it<sup>53</sup>.

Veimer also noted that integration had been limited to date among different agencies providing substitution treatment. Most notably, methadone is currently provided in Estonian prisons through the Ministry of Justice (even though needle and syringe exchange remains barred). However, there is no system in place to help ensure substitution treatment continuity for clients moving in and out of penitentiary facilities, i.e., from one jurisdiction (the justice or social affairs ministry) to another. The situation is even more complicated because individuals held in pre-trial detention are under the responsibility of the Ministry of Internal Affairs, which does not provide methadone at any of its facilities.

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<sup>53</sup> Interviewed in Tallinn, April 21, 2008.